Diabetes Education Services Presents:

ReVive 5 Diabetes Training Program

Session 1 |2024

Optimize self-care based on personal choice and values—
"find the expert within."

Program Faculty

- Lawrence Fisher, Ph.D., ABPP, Professor Emeritus, UCSF
- Susan Guzman, PhD
- Beverly Thomassian, RN, MPH, CDCES, BC-ADM

Land Acknowledgment

- We acknowledge and are mindful that Diabetes Education Services stands on lands that were originally occupied by the first people of this area, the Mechoopda, and we recognize their distinctive spiritual relationship with this land, the flora, the fauna, and the waters that run through this area.

Diabetes Education Services Inclusion Statement

Based on the IDEA Initiative inspired by CDR

- Inclusion
- Diversity
- Equity
- Access

- We are committed to promoting diversity and inclusion in our educational offerings.
- We recognize, respect, and include differences in ability, age, culture, ethnicity, gender, gender identity, sexual orientation, size, and socioeconomic characteristics.
- Our goal is to promote equity and access, acknowledging historical and institutional inequities.
- We are committed to practicing cultural humility and cultivating our cultural competence.
- We wish to create a safe space within our community where one's beliefs, experiences, identity, and differences in ability, age, size, socio-cultural/socioeconomic characteristics, and political affiliations are considered and respected.

Introducing the ReVive Team

- **ReVive 5 is taught by a team of 3 Interdisciplinary Experts:**
- Lawrence Fisher, Ph.D., ABPP, Professor Emeritus, UCSF
- Susan Guzman, PhD
- Beverly Thomassian, RN, MPH, CDCES, BC-ADM

All speakers have no conflict of interest to report.

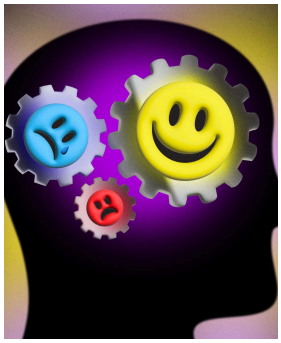
- Speakers are not on any speaker's bureau
- They not invest or have any financial relationships with diabetes related companies.
- All information in program are from reading package inserts, research and articles.

Managing Type 1 Diabetes Is Tough

- A huge amount to manage and balance
- No vacation – constant & unrelenting
- Efforts never good enough
- Frightening: hypers, hypos, complications, costs
- Most others don't see the amount of work involved
- Difference between T1D and T2D, but both can be tough.

Diabetes Distress (DD)

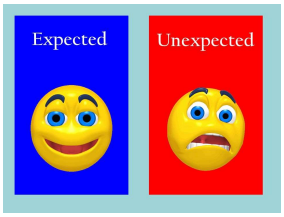
- All of this creates an emotional toll, which reflects *the emotional side of living with diabetes*.
- We use the generic term *"Diabetes Distress"* to reflect the broad range of feelings, beliefs and expectations that result from struggling with diabetes over time.



DD Is To Be Expected

Distress is an *expected* response to living with any chronic health condition and is not psychopathology or a co-morbid condition.

DD is simply the **emotional side of living with diabetes**



DD can show itself in many forms

Most common:

- May not show itself outwardly.
- Feelings of frustration, powerlessness, hopelessness.
- Pronounced fear of hypos or complications.
- Avoidance of tough feelings "Who me?" "Everything is fine."
- Burnout because of all of the management tasks, frustrating results, dealing with insurance.
- Anger/frustration with providers: distrust, no-shows.
- Hyper attention to CGM screens and excessive BG checking.

DD can show itself in many forms

- How it is expressed and its intensity can vary over time.
- Can increase with diabetes-related events (change in medications or dosage or change in new technologies).
- Occurs across the A1C spectrum (perhaps for different reasons/different sources): **don't assume that DD is low if A1C is below 7.0%.**

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Poll Question 1

Which of the following is NOT a component of Diabetes Distress?

- A. Feeling powerless with diabetes
- B. Challenges with healthcare professionals
- C. Concerns about hypoglycemia
- D. General life stress

Poll Question 2

Which of the following is true?

- A. DD is a form of psychopathology.
- B. DD refers to the emotional side of diabetes.
- C. DD is expressed in the same way over time.
- D. DD occurs only among individuals with a high HbA1C.

Why is DD Important?

DD is significantly linked cross-sectionally and over time with:

- A1C: high DD associated with high A1C (TIR) (*but impactful throughout the entire A1C range*)
- Low Heart Rate Variability, a CVD risk factor
- Reduced medication/insulin taking
- Missed healthcare visits
- Increased risk of hospitalization
- Less physical activity
- Weight and dietary problems
- Lower quality of life
- Increased costs

DD has a highly significant clinical impact!

Ehrmann, et al., 2023; Fisher et al., 2015, 2016, 2018; Hessler, et al., 2017

ADA Standards of Care 2024

Diabetes Distress Recommendation

- **5.42** Routinely monitor people with diabetes, caregivers, and family members for diabetes distress, particularly when treatment targets are not met and/or at the onset of diabetes complications.
- Diabetes distress should be routinely monitored using diabetes-specific validated measures. If diabetes distress is identified, it should be acknowledged and addressed.

(Diabetes Care, 2024)

DD Prevalence

- High prevalence among adults (T1D = 74%, T2D = 62%; but 97% of those with T1D and 87% of those with T2D express concerns in at least one area of living with diabetes): DD is "ubiquitous."
- DD does not disappear on its own (easily becomes chronic without intervention): of those adults with T1D and high DD at baseline, 74% screened positive 9 months later.

Fisher, et al., 2024; Polonsky, et al., 2023

Poll Question 3

Which of the following is false?

- A. DD is episodic.
- B. DD is highly prevalent.
- C. DD is linked to diabetes management.
- D. DD has a significant clinical impact.

What About Depression and Distress?

- DD is distinct from clinical depression or Major Depressive Disorder (MDD); *but it can be confusing.*
- 'Depression' is measured in different ways: depressed affect, symptoms of depression, or a clinical diagnosis of MDD.
- Depression is most often assessed using symptom screeners, e.g., PHQ9.
- A diagnosis of "clinical depression" or MDD requires a structured clinical interview, not a symptom screener.

Fisher, et al., 2016, 2018; Gonzalez, et al., 2013

Depression, DD, and Diabetes

- Most people with diabetes who display elevated symptoms of "depression" from screeners DO NOT meet criteria for MDD.
- The false positive rate of screeners is very high: 54% in ACCORD, 79% in REDEEM.
- Correlations between depression screening scales and DD scales are very high (0.60), suggesting that much of what *depression screening scales measure is really the tough feelings of DD*.
- ***Among those with diabetes, much of what we might think of as 'depression' is really elevated DD***

Fisher, et al, 2016; Sullivan, et al., 2012

Depression vs. Diabetes Distress?

Depressive Disorder

- Hopelessness about life in general.
- Pervasive and persistent mood problems (most of the day, more days than not).
- Interferes with functioning across domains (relationships, work, health).

"I'm a failure. Everything is hopeless."

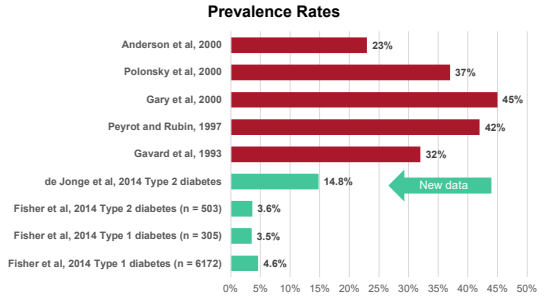
Diabetes Distress

- Sadness and tough feelings about diabetes.
- Persistent stressors related to diabetes.
- May or may not affect diabetes management or functioning in other areas.

"I'm failing at diabetes. My efforts at diabetes are hopeless."

Prevalence Of Depressive Disorders

For those with diabetes



Conclusions About Depression & DD

- DD and 'depression' may look similar (especially on screeners), but they are *very* different.
- ADA guidelines suggest that DD be assessed and managed *within* diabetes care – no need to refer.
- This means that *you* are the front-line, DD interventionists – *and you can do it!*

NOTE: *MDD does occur in the diabetes population. When detected and diagnosed adequately, it needs to be addressed.*

Poll Question 4

What percent of adults with T1D who meet criteria for elevated DD?

- A. About 75%
- B. About 50%
- C. About 30%
- D. Less that 20%

Poll Question 5

Which of the following are true (check all that apply)?

- A. Much of what is measured by depression screening scales is really elevated DD.
- B. Depression screening scales often yield a high rate of false positives.
- C. Depressive disorder reflects feelings of hopelessness about life in general.
- All of the above.

Summary Of What We Know About DD

- It is alarmingly prevalent and is an expected part of living with diabetes.
- It highly clinically significant *at any level*.
- Best not to assess DD with summary scores or brief screeners – use comprehensive measures.
- Much of what we might think of as depression is really elevated DD.
- You are the front-line DD interventionists.

How does DD impact diabetes management?

DD serves as a *barrier* to improved management. People who are distressed display:

- Less energy and motivation.
- Reduced engagement in management.
- Less ability and willingness to make helpful management choices, which leads to further DD.

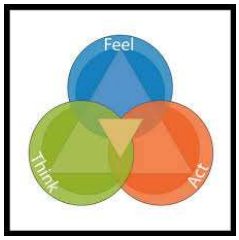
Fisher, et al., 2018; Hessler, et al., 2021

Why Does DD Lead To Problematic Management Choices?

How you feel and what you think drives the choices you make!

<u>Feelings and beliefs drive behavior!!</u>

And this plays out in diabetes as it does in other areas of life.



Why Does DD Lead To Problematic Management Choices?

<u>Examples</u>:

- If you feel that you are powerless to keep BG in range, why try?
- If you think that you will never be safe from a low, why take the right amount of insulin?
- If you feel your efforts are never good enough, why bother trying something new?
- If you are tired being told that you are not doing well with your diabetes, why go to the doctor to hear it again?

DD Is A Barrier To Change

DD serves as a *<u>barrier</u>* to improved management and wellbeing. People who are distressed generally display:

- Less energy and motivation.
- Reduced engagement in management.
- Less ability and willingness to make helpful management choices and changes, which leads to further DD.

Fisher, et al., 2018; Hessler, et al., 2021

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Poll Question 6

Which of the following is true?

- A. Distress often motivates people to make better management choices.
- B. High DD is associated with greater engagement.
- C. High DD reduces energy for self – management.
- D. All of the above.

Reducing DD: The Good News!!

DD is highly malleable:

- Highly responsive to intervention.
- Dramatic reductions can occur quickly.
- Interventions do not have to be time-consuming or require extensive mental health training.
- Similar findings for adults with T1D or T2D.

Reducing DD: The Good News!!

Significant reductions in DD using emotion-focused interventions (vs. CBT and education-based interventions).

New EMBARK findings: emotion-focused interventions led to the largest DD *and* A1C improvements.

Also found both decreased frequency of hypos and missed boluses.

Reductions in DD are significantly correlated with reductions in A1C.

Fisher, et al., 2017; Hessler, et al., 2018; Fisher, et al., 2018.

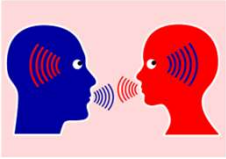
Addressing DD in clinical care requires a different kind of conversation!

Let's review some important assessment and intervention tools to help make this happen.

Conversational Tools You Can Use To Address DD In Your Practice

The idea is to use these tools to help build a relationship with the PWD that will effectively address the emotional side of diabetes.

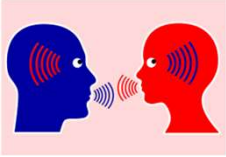
You may already be familiar with these tools – our goal here is to target them specifically and apply them to DD.



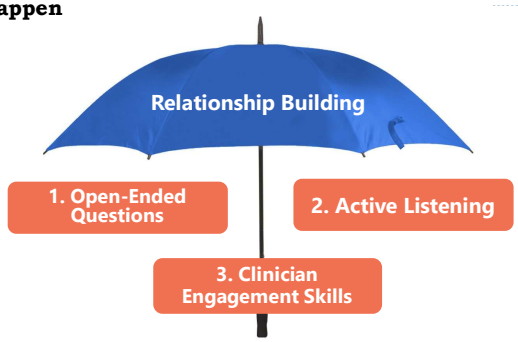
Conversational Tools You Can Use To Address DD In Your Practice

The goal is to help the PWD label, verbalize, share, consider, and evaluate these frequently unaddressed and often hidden feelings and thoughts about diabetes.

Building the relationship with conversational skills is the intervention!



Relationship Building | Three Tools To Make It Happen



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Tools | #1. Open-Ended Questions

What are *closed-ended* questions?

Answers have to do with short, fixed responses (*that then require a clinician to then ask the next question*).

- Examples of *closed-ended* questions:
  - - What kind of exercise do you like to do? "Walk!"
    - How often do you walk? "3-times a week."
    - How often do you check your BG? "Five times a day."

Closed-ended questions do not help address DD.

Tools | #1. Open-Ended Questions

What are *open-ended* questions?

Questions that ask "how, what, why."

They require a more detailed response.

Examples:

"How do you respond when you go low?"

"What worries you the most about your diabetes?"

"What sense do you make of these BG numbers?"

"Why do you think that you are having trouble lowering your BG levels? What might be going on?"

Open-ended questions sometimes make clinicians nervous(never know what the response might be) –but they open the door to a more effective clinical conversation.

Tools | #2. Active Listening

What is "active listening?"

- Listen attentively – talk much less (< 50%).
- Alter tone and pace of speech (tolerate silences).
- Attend to the position of HCP and PWD in the room.
- Maintain eye contact (engage physically).
- Prevent computer, charts, papers, from distracting.

Create an atmosphere of engaged, empathetic, and attentive listening.

Tools | #3. Clinical Engagement Skills

Based on MI, empowerment, autonomy support:

1. Label Feelings and Beliefs
2. Summarize & Reflect
3. Normalize & Accept

Clinical Engagement Tools: Label & Address Feelings

- Many people are unaware of what they feel.
- Many feel many things at the same time – hard to separate and label each (anger and self-blame).
- Many are ashamed or embarrassed about what they feel – "I shouldn't feel this way."
- Listen carefully for underlying feelings throughout the conversation.

Clinical Engagement Tools: Label & Address Feelings

TOOL: Sprinkle feeling words throughout the conversation.

- Use the conversation to focus on feelings – label them explicitly.
- Practice using these words – pick ones that fit your style.
- Expect some people to be surprised at your use of feeling words (no one ever talked to them this way).
- Don't worry about saying the wrong feeling word – they will correct you.
- Examples:

  "Sounds like you were really *frustrated* about …"
  "You must have ended up feeling *disappointed* …"
  "Perhaps you were feeling it was *your fault* anyway, yet you seem to be angry at them at the same time."

Clinical Engagement Tools: Label & Address Feelings

Common feeling words:

- Sad
- Frustrated
- Scared/fearful
- Disappointed
- Angry
- Hopeless
- Defeated
- Ashamed/embarrassed
- Burned out

Clinical Engagement Tools: Summarize & Reflect

- It helps the PWD know that you are listening carefully and are interested.
- It helps them know that you understand & accept without judgement.
- It helps them to evaluate and consider their own experience – it becomes more objective, since the repetition comes from you (from outside of their own head).
- It helps them consolidate/integrate their experience, feelings and reactions (puts the entire picture together).

Clinical Engagement Tools: Summarize & Reflect

TOOL: Periodically summarize and repeat back without judgement.

- Do not fix or correct anything, even if it might be factually incorrect.
- Add feeling words, even if they were not used originally.
- Emphasize that this is a way to make sure that you understand and have it right.

  "So you are saying that … Do I have that right?"
  "Let me see if I understand (this happened, that happened, you reacted, etc.; that must have left you feeling…"

Clinical Engagement Tools: Normalize & Accept

TOOL: Comment often that how they feel makes sense, that their feelings and experiences are very common among PWDs, and that it is OK that they feel this way – *it is just being human and having tough feelings about a tough disease*.

"Anyone going through this would feel the same way"
"Many of the people I see with diabetes feel exactly the way you do."
"If I were in your shoes, I'd probably feel the same way."
"It makes sense that you would feel that way, given what is happening."

Poll Question 7

Which of the following can be used as a conversational tool?

- A. Use closed-ended questions to speed up the interaction.
- B. Keep your clinical reports and records in front of you to use for reference.
- C. Don't use too many feeling words because you might embarrass the PWD.
- D. Accept the PWD's experience without judgement.

Poll Question 8

Which is NOT a good example of a conversational tool?

- A. Speak frequently to gather information and save time.
- B. Correct inaccuracies or misperceptions when they arise.
- C. Point out when they are overreacting.
- D. All of the above.

Now let's take these Clinical Engagement Tools and use them as part of a *practical* 5-step plan to reduce DD and enhance management.

ReVive5: A Five Step Plan

1. Assess DD regularly and systematically using the T1-Diabetes Distress Assessment System (T1-DDAS).
2. Begin a conversation to foster a new or different perspective.
3. Consider different management choice(s) that are not driven by tough thoughts and feelings.
4. Optimize management based on personal choice and values – find the expert within.
5. Make changes and plan for next steps

A Warning Before We Begin

- You may feel that you don't have the time to do this.
- Can't I just refer this person to someone else (*who*?)?
- A focus on feelings may make you uncomfortable. Not in your job description or what you were trained to do.

DON'T PANIC:
This is a normal reaction.
Building new skills takes time/practice/patience.
Give it a try, we are here to help.
Suspend judgement for now and go with the flow!

ReVive5: A Five Step Plan

1. **Assess DD regularly and systematically using the T1-Diabetes Distress Scale (T1-DDS).**

2. Begin a conversation to foster a new or different perspective.

3. Consider different management choice(s) that are not driven by tough thoughts and feelings.

4. Optimize management based on personal choice and values – find the expert within

5. Make changes and plan for next steps

1. Assess DD Regularly, Systematically & Comprehensively With Everyone

WHY?

- Makes no sense providing education/intervention when DD will limit responsiveness.
- Regular assessment makes it part of your clinical routine – harder to forget or skip.
- Assessment is comprehensive – leaves no important gaps.
- The results can be used to start an intervention through a clinical conversation.
- Change can be assessed over time.

Measuring Diabetes Distress

Major tools to measure DD:

- **T2-DDAS (Type 2 Diabetes Distress Assessment System): developed 2022**
  - 8 item core scale, 21 items with 7 subscales.
- **T1-DDAS (Type 1 Diabetes Distress Assessment System): developed 2024**
  - 8 item core scale, 30 items with 10 subscales.
- **Others**: PAID, T1-DDS, DDS.

If these tools are not available (as a last resort):

- "Can you tell me something about what it's been like for you living with diabetes recently?"
- "Can you tell me what bothers you most about life with diabetes?"
- "On a scale from 1 to 5 can you tell me how stressed you feel by the demands of living with diabetes?"

The T1-Diabetes Distress Assessment System (T1-DDAS)

For adults with T1D: 30 items.

- 8-item Core Scale: intensity/extent of DD
- Ten, 2- or 3-item Source Scales: where DD comes from

- Financial Worries
- Interpersonal Challenges
- Management
- Hypo Concerns
- Healthcare Quality
- Shame, stigma
- Lack Of Diabetes Resources
- Technology Challenges
- Burden To Others
- Worries About Complications

Each has a cut-point (>2.0) that defines elevated DD.

The T2-Diabetes Distress Assessment System (T2-DDAS)

For insulin & non-insulin adults with T2D:

- **8-item Core Scale: intensity/extent of DD**
- **Seven, 3-item Source Scales: where DD comes from**

- **Hypo Distress**
- **Long-term health (complications)**
- **Healthcare provider (trust, relationship)**
- **Interpersonal issues (work, family)**
- **Shame, stigma**
- **Healthcare access**
- **Management demands (meds, food, exercise)**

The TOTAL & each Source score related to QOL & management.

Each has a cut-point (>2.0) that defines elevated DD.

Only the Core score is used in prevalence studies

The T1-Diabetes Distress Scale

How To Administer?

- Smart phone prior to appointment (Print/Save PDF)
- Tablet or computer kiosk in the waiting room (most common)
- Tablet or computer in your office
- Hard copy form in office or waiting room
- The T1/T2-DDAS results can be integrated into your EHR

Diabetesdistress.org

On this site you will find:

- Background information on diabetes distress for patients and providers.
- Links to other diabetes distress resources.
- Online and pdf versions of the Diabetes Distress Scales in several languages.
- Definitions of each scale and sub scale.
- Information about how each scale is scored.

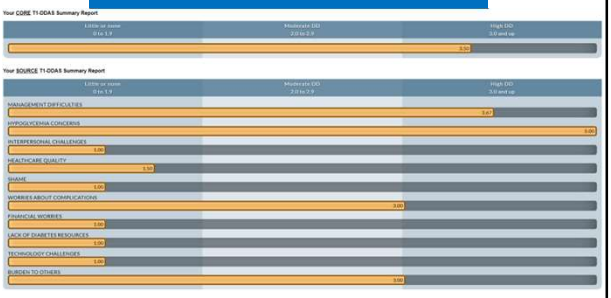
T1-DDAS in English & Spanish for download

T1-Diabetes Distress Assessment System

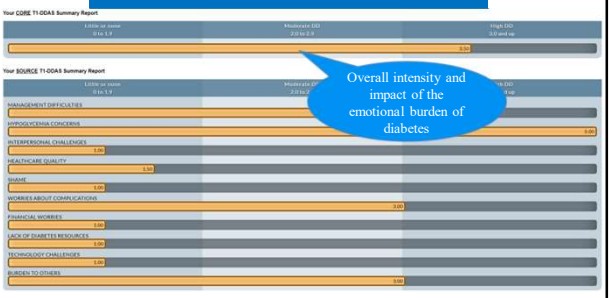
Obtain the T1/T2-DDAS at:
www.diabetesdistress.org

- Download PDF of the questionnaire in English or Spanish, with scoring instructions.
- Administer the T1-DDAS online using a smartphone, tablet or computer: the site will automatically score it for you.
- The site will automatically prepare a report with scored subscales and items for review online or for download as a pdf.

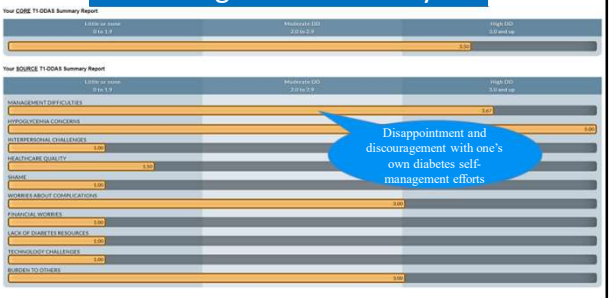
T1-DDAS Core and Source Scales



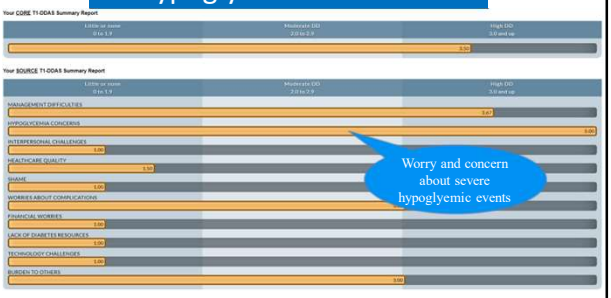
Core Distress Scale



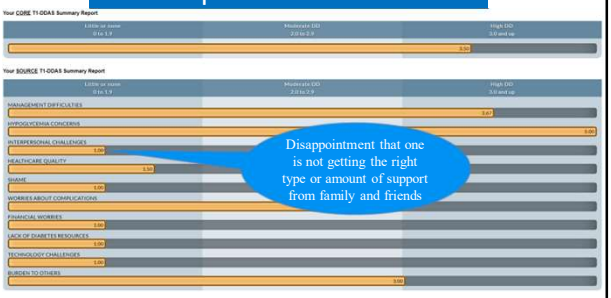
Management Difficulty



Hypoglycemia Concerns



Interpersonal Concerns



Healthcare Quality

Shame

Your CORE T1-DDAS Summary Report

Little or none 0 to 1.9	Moderate DD 2.0 to 2.9	High DD 3.0 and up
3.50		

Your SOURCE T1-DDAS Summary Report

Little or none 0 to 1.9	Moderate DD 2.0 to 2.9	High DD 3.0 and up
MANAGEMENT DIFFICULTIES	3.67	
HYPOGLYCEMIA CONCERNS		5.00
INTERPERSONAL CHALLENGES	1.00	
HEALTHCARE QUALITY	1.50	
SHAME	1.00	
WORRIES ABOUT COMPLICATIONS	3.60	
FINANCIAL WORRIES	1.00	
LACK OF DIABETES RESOURCES	1.00	
TECHNOLOGY CHALLENGES	1.00	
BURDEN TO OTHERS	3.00	

Concern about the reaction of others to knowledge of their diabetes

Worries About Complications

Your CORE T1-DDAS Summary Report

Little or none 0 to 1.9	Moderate DD 2.0 to 2.9	High DD 3.0 and up
3.50		

Your SOURCE T1-DDAS Summary Report

Little or none 0 to 1.9	Moderate DD 2.0 to 2.9	High DD 3.0 and up
MANAGEMENT DIFFICULTIES	3.67	
HYPOGLYCEMIA CONCERNS		5.00
INTERPERSONAL CHALLENGES	1.00	
HEALTHCARE QUALITY	1.50	
SHAME	1.00	
WORRIES ABOUT COMPLICATIONS	3.60	
FINANCIAL WORRIES	1.00	
LACK OF DIABETES RESOURCES	1.00	
TECHNOLOGY CHALLENGES	1.00	
BURDEN TO OTHERS	3.00	

Concerns about the potential health problems diabetes may cause over time.

Financial Worries

Your CORE T1-DDAS Summary Report

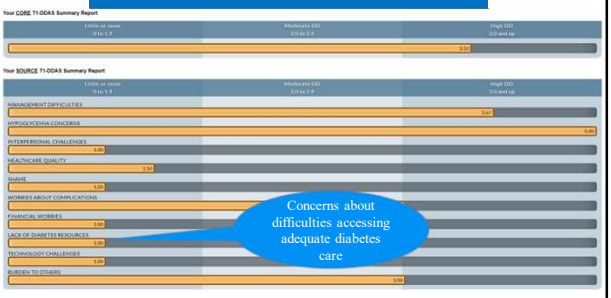
Little or none 0 to 1.9	Moderate DD 2.0 to 2.9	High DD 3.0 and up
3.50		

Your SOURCE T1-DDAS Summary Report

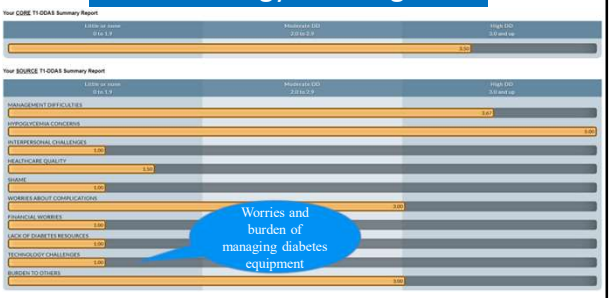
Little or none 0 to 1.9	Moderate DD 2.0 to 2.9	High DD 3.0 and up
MANAGEMENT DIFFICULTIES	3.67	
HYPOGLYCEMIA CONCERNS		5.00
INTERPERSONAL CHALLENGES	1.00	
HEALTHCARE QUALITY	1.50	
SHAME	1.00	
WORRIES ABOUT COMPLICATIONS	3.60	
FINANCIAL WORRIES	1.00	
LACK OF DIABETES RESOURCES	1.00	
TECHNOLOGY CHALLENGES	1.00	
BURDEN TO OTHERS	3.00	

Concerns about the affordability of diabetes supplies

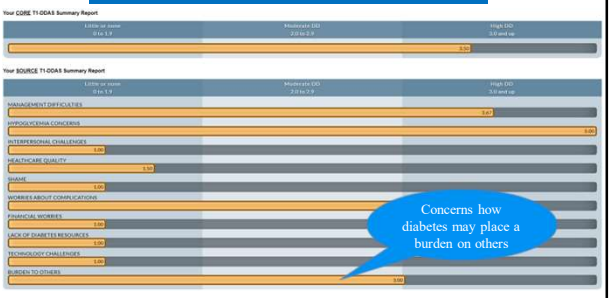
Lack of Diabetes Resources



Technology Challenges



Burden To Others



T1-DDAS Item Report

Question	Not a Problem (1)	A Slight Problem (2)	A Little Problem (3)	A Serious Problem (4)	A Very Serious Problem (5)
Core Level Of Distress					
I feel burned out by all of the attention and effort that diabetes demands of me.			✓		
It bothers me that diabetes seems to control my life.				✓	
I am frustrated that even when I do what I am supposed to for my diabetes, it doesn't seem to make a difference.				✓	
No matter how hard I try with my diabetes, it feels like it will never be good enough.				✓	
I am so tired of having to worry about diabetes all the time.				✓	
When it comes to my diabetes, I often feel like a failure.					✓
It depresses me when I realize that my diabetes will likely never go away.	✓				
Living with diabetes is overwhelming for me.			✓		
Management Difficulties					
I feel discouraged when I see high blood glucose numbers I can't explain.				✓	
I feel that thoughts about food and eating control my life.			✓		
I get angry at myself for not managing diabetes better.				✓	
Hypoglycemia Concerns					
I worry a lot that I could have a serious low glucose event.					✓
I feel so scared of going low that I avoid things in my life.					✓

How to Use the T1-DDS

Getting started:

"Living with diabetes can be tough and we are interested in learning about how you are feeling about your diabetes and how it affects your management (or referring problem). We would like you to complete this brief scale and we will review the results together."

How to Use the T1-DDAS

- Once the T1-DDAS has been completed and printed, it is time to have a very different kind of conversation.
- This requires *you* to make a big shift in style, timing and tone.
- In this conversation, you are not talking and problem solving, you are listening and helping the PWD *tell their DD Story*.
- Use the relationship building tools we reviewed to make this happen.

Poll Question 9

It is always best to assess DD when:

- A. You suspect high DD.
- B. You have a new PWD in your practice.
- C. With each PWD regularly and systematically.
- D. Only if you have time.

Poll Question 10

It is always best to:

- A. Only focus on the T1-DDAS Core score.
- B. Focus only on the high T1-DDAS Source Scale scores.
- C. Focus only on the highest items.
- D. None of the above.

SUMMARY SO FAR

- We have reviewed the Clinical Conversational Tools.
- We have outlined the ReVive5 plan to reduce DD and enhance management
- We have reviewed Step-1 of the plan – assessing DD systematically using the T1-DDAS.

ReVive5: A Five Step Plan

1. Assess DD regularly and systematically using the T1-Diabetes Distress Scale (T1-DDAS).

2. Begin a conversation to foster a new or different perspective.

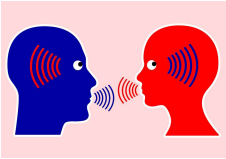
3. Consider different management choice(s) that are not driven by tough thoughts and feelings.

4. Optimize management based on personal choice and values – find the expert within

5. Make changes and plan for next steps

Step #2: A Different Kind Of Conversation

Your Task:
Help them tell their Diabetes Story about these highly scored items using the Conversational Tools



Step #2: A Different Kind Of Conversation

What is a DD story? *Using the high T1-DDAS scores, one recent example of:*

- What they are distressed about (e.g., lows, cannot 'control' their BG or eating)?
- Their feelings and thoughts about it – what it means to them
- How they choose to manage their diabetes in reaction to their DD?
- What they would have liked to have done but didn't?

The brief story tells you the "good reason" why a person is making their current choices. (If terrified you cannot be safe, you stay high.)

Getting The Conversation Started

"To prepare for this visit, you completed a questionnaire that looks at Diabetes Distress. This questionnaire reflects how stressed you are about diabetes right now and what you might be stressed about.

Can we take a look at your results together?"

Getting the Conversation Started

Start by identifying high Source scores:

"What strikes you about these scores? You scored 'management difficulties' quite high. Can tell me more about why you are feeling this way?"

Then identify all highly scored items:

"I notice that you scored high on the item: 'Feeling that food and eating control my life.' Can you tell me what might be going on?"

Having A Different Kind Of Conversation

Use the T1-DDAS printout and worksheet to gently structure the conversation:

First: Ask for a specific recent experience (example) that captures the issue reflected in the highly scored item(s).

Generate discussion about these 5 points to make the Story clear. (*Use the Worksheet to help keep the conversation focused.)*

- What happened during the experience?
- What were your thoughts/feelings?
- What did you actually do (specifically)?
- How did it turn out?
- Ideally, what would you have liked to have happened?

<u>This Is Their Diabetes Story</u>

Having A Different Kind Of Conversation

Establish a "judgement-free" environment.
Most have never been asked how they feel or think about their diabetes and can elicit painful feelings and thoughts.
We may not be used to hearing & tolerating this (painful and uncomfortable for us too)

- May want to jump in and make them feel better
- May feel that you don't have the time for this or that it is not part of your professional role
- Remember: you do not have to "fix" them (no need to rescue them, solve it, or make them feel better – just elicit the story)

Diabetes Distress Stories

Common events you will hear about:

- Scary or embarrassing lows
- Surprising highs
- Difficulty managing BG
- Eating challenges
- Managing all of the tech
- Situations with friends, family, colleagues
- Managing health care (feeling judged and misunderstood), insurance, etc.

Diabetes Distress Stories

"Can you tell me about a recent example of this DD item?"

"I had a low right before I was to drive to a big family wedding."

"I could not get my sugars down – nothing I did seemed to work."

"At a family dinner everyone kept looking at me when I reached for dessert."

Having the Conversation

Listen for major common themes: (*Referenced in handout*)

- Hopelessness/powerlessness: "No matter what I do, I can't control my diabetes"
- Negative self- judgement: "It is all my fault – I am a bad diabetic. I should be able to do it by now."
- Shame: "I don't tell people I have diabetes." "I keep my challenges to myself."
- Burden: "I am a burden on my family, friends and the healthcare system."
- "I am broken" (damaged goods): "I am not as attractive to others because of diabetes"
- Doom/Fatalism: "I am destined for terrible complications"

Having the Conversation

Use The Conversational Tools:

- Reflect often with empathy and use "feeling" words: "That must have really frustrated you." "You must have been so angry."
- Common "feeling" words: anger, fear, frustration, exhaustion, sad, embarrassed, guilty, overwhelmed, etc. They will correct you if you are wrong.
- Listen for how they are self-critical and beat themselves up (I'm a bad diabetic." "I should know this by now.").

Having the Conversation

Review and summarize the story you hear:

"Do I have this right?"
"Is there anything missing?"

Then ask:

"How does all of this strike you?"
"Does any of this surprise you?"

Poll Question 1

Which of the following is NOT part of Having A Different Kind Of Conversation?

A. Ask for a specific experience or example

B. Tell them about new devices that could help

C. Establish a judgement free zone

D. Use the conversational tools

Having the Conversation

An Illustration of ReVive Steps 1 and 2:

You will now hear conversation that illustrates the use of the tools and how to get the conversation started. See if you can notice each of the conversational tools. Refer to your packet where each of the tools is highlighted in the conversation:

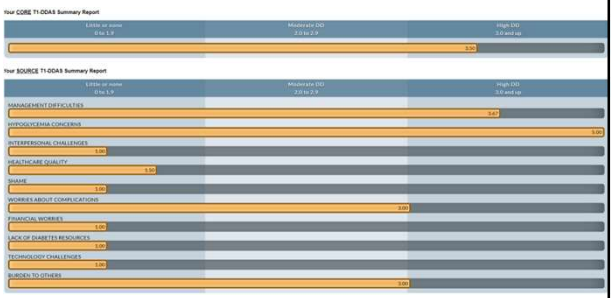
- Open-ended questions (O)
- Reflecting feelings words (R)
- Summarizing (S)
- Normalizing (N)
- Active listening with empathy (E)

Meet Sally

- 45 years old, T1D for 30 years, lives with husband, two teens
- On CSII, but no CGM (disappointed after trying one many years earlier)
- Recent A1C results: 7.4%, (9 months later) 8.8% (and 8 lb weight gain)
- Referred to Diabetes Education for "medical nutrition counselling"

Let's Ask Sally

"Before we get started, I wanted to ask you to complete a brief questionnaire that looks at how you are feeling about your diabetes right now. We know that tough thoughts and feelings are really common for people with T1D and can make diabetes even harder to live with and manage." *(N)*



Core Scale and Highest Source Scale Items

Question	Not a Problem (1)	A Slight Problem (2)	A Little Problem (3)	A Serious Problem (4)	A Very Serious Problem (5)
Core Level Of Distress					
I feel burned out by all of the attention and effort that diabetes demands of me.			✓		
It bothers me that diabetes seems to control my life.				✓	
I am frustrated that even when I do what I am supposed to for my diabetes, it doesn't seem to make a difference.				✓	
No matter how hard I try with my diabetes, it feels like it will never be good enough.				✓	
I am so tired of having to worry about diabetes all the time.				✓	
When it comes to my diabetes, I often feel like a failure.					✓
It depresses me when I realize that my diabetes will likely never go away.	✓				
Living with diabetes is overwhelming for me.			✓		
Management Difficulties					
I feel discouraged when I see high blood glucose numbers I can't explain.				✓	
I feel that thoughts about food and eating control my life.			✓		
I get angry at myself for not managing diabetes better.				✓	
Hypoglycemia Concerns					
I worry a lot that I could have a serious low glucose event.					✓
I feel so scared of going low that I avoid things in my life.					✓

Let's Ask Sally

"Looking at your T1-DDAS results, it seems like T1D is really getting you down, especially when it comes to hypoglycemia.(R) Can you tell me more? (O) Can you give me an example so that I can understand more about how you are feeling?"(O)

And Sally Responds…

"I had a bad low two months ago – got down to 40 mg/dL at night and woke up only because my dog was barking. I'm worried I can't feel my lows anymore."

"That sounds really frightening.(E,R) How has that affected how you feel and impacted your diabetes management?" (O)

"It was terrifying. And to be honest, I have been scared ever since this happened. Since that bad low, I have had trouble sleeping for fear of another low that I don't wake up from. I now drink a milkshake before bed just to try and stay safe.

"Many people with T1D intentionally stay high after having a scary low. (N) It is a logical response to not feeling safe. (R) Unfortunately, then the person often feels bad about themselves and has lots of highs and weight gain. (N) Does that fit your experience?" (O)

"Yes. I feel like an idiot. I have had diabetes for 30 years. If I can't get this right or perfect by now, I don't think I will ever will."

"No wonder you are feeling so down about your diabetes.(E, R) Since you had that really terrifying experience of a low at night you woke up from only because your dog barked, you have been trying to feel safe by having a milkshake before bed. Now you are having highs and weight gain and feeling pretty hopeless about your diabetes management. (R, S) Did I get that right?" (O)

"Yes. It really is a tough spot."

"In your ideal scenario, what would you have liked to have happened after that scary low, instead of what has happened since then?" (O)

"I would have just realized that lows occasionally happen and moved on, like I have at other times. I would tolerate going to bed with a lower BG and certainly wouldn't be drinking a milkshake before bed!"

Summary So Far

1) You have assessed DD and reviewed the results

2) You have used the conversational tools to help the PWD tell their diabetes story of a recent event that illustrated the DD item.

Did you notice when the HCP:

- Asked open-ended questions
- Used feeling words
- Summarized statements
- Normalized tough experiences
- Used active listening with empathy

Summary So Far

You have heard Sally's "Diabetes Distress Story". She told us of a recent event that illustrated the DD item:

- What happened during the experience
- What her thoughts/feelings were
- What she actually did (specifically)
- How it turned out
- What she would have liked to have happened that didn't
- How this has impacted her management choices

This DD story opens the door to foster a new perspective…

Having the Conversation – Part 2

Foster A New Perspective

Key points:

- People have tough thoughts and feelings about diabetes *("I can never be safe from hypos")*
- Many react to these thoughts/feelings with certain actions *("I drink a milkshake before bed")*
- These DD-driven choices do not really get them closer to their goals (what they want). ("*I would've liked to have moved on after that low and tolerated a lower BG before bed")*

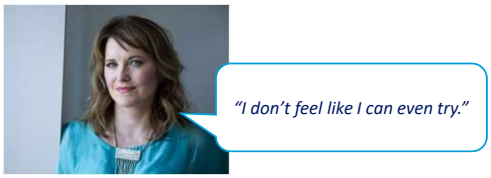
Foster A New Perspective

Key points (cont'd):

- Telling the DD story out loud helps the person see how DD keeps them stuck.
- Adopting another perspective allows them to consider other choices/actions that can take them closer to their goals.

Let's Ask Sally

"How do you think your fear of having another severe low and believing that you will never get this right or perfect keeps you stuck and prevents you from doing things differently?"



Help Foster A New Perspective
Separating Thoughts/Feelings From Actions

- People can feel/think one way and act another!
- People can make other choices, even though they have tough feelings.
- Your job is to help them set their feelings/thoughts aside (tolerate them) so that they can make different choices.
- These new choices are to move them closer to what they really want to happen.

Separating Thoughts/Feelings from Actions

What to do:

First, demonstrate how their distress is currently driving an action they really don't want to happen.

Separating Thoughts/Feelings from Actions

Example:

"I know that you have had a few bad lows at night in the past. But this time it was different: it really scared you. And then you started going to bed high, taking less insulin at night. It seems that it is not the low itself, but your fear of another low that is driving you to do things that are not helpful. Do I have this right?"

This separates the feelings that drive the behavior from the behavior itself.

"Sometimes the tough thoughts and feelings that you have been describing make it hard to make changes. The thoughts and feelings keep you stuck. When this happens, managing your diabetes is obsessed by the tough thoughts and feelings, not by what you really want to happen."

"For example, when that scary low happened, you felt fearful that you could never be safe from a severe low while sleeping again. Then you responded by keeping your BG high at night. But, if you could have set these thoughts/feelings aside, you would have preferred to recognize lows occasionally happen and would go to bed with a lower BG. Does this make sense?"

"Yes, that completely makes sense."

Separating Thoughts/Feelings from Actions

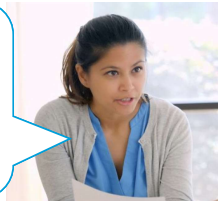
After the connection is made, ask if they are willing to consider another choice (based on what they really want to happen).

"Can you set these tough feelings aside and choose to do something different?"

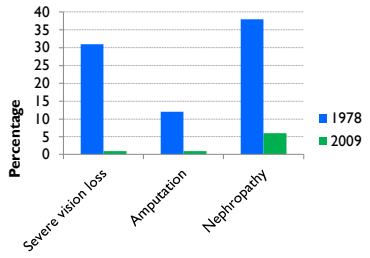
"Can you decide that these tough feelings are not going direct what is best for you?"

"Can you be afraid and take a different action to get you closer to your goals?"

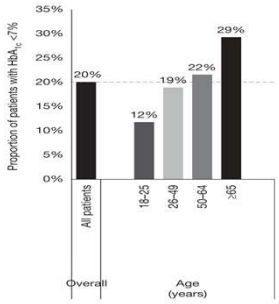
"Anybody that went through such a scary experience, might feel the same way. Do you think that you can tolerate your fear of lows in order to make a different choice that takes you closer to your goals?"



Frequency of Complications After 30+ Years: A big change

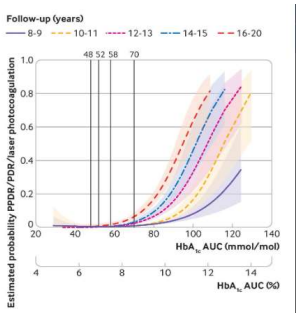


A1C Expectations: Percentage of People with T1D Achieving ADA A1C Target



Pettus et al, 2019

A1C and Risk of Retinopathy



Lind et al, 2019

A1C is Only Part of the Risk Story

A1C only accounts for between 15-50% of the complications risk story.

Other factors associated with risk of complications independent of A1C are:

1. BG variability (above and below target range: 70 to 180)
2. Physiological factors: body composition, BP, LDL
3. Genetic factors

Important message: **You can only do the best you can with what is possible to change!** (You can't pick your parents!)

Examples of More Helpful Expectations

- Perfect isn't possible and you don't need to be (healthy good enough) *"Do you have to be perfect to be healthy?"*
- Having a tough time with a tough disease is normal. *"Most people with DM find it tough going – this is not you, it is diabetes."*
- You are not alone if you struggle with diabetes and/or have challenges with the emotional side of diabetes

<u>These more helpful expectations are about keeping diabetes in perspective</u>

Help Establish Helpful Expectations

What to do:

- Acknowledge the common DD Story *("Many people with T1D struggle with trying to be perfect.")*
- Connect their story to the <u>unhelpful expectations</u> that keeps them stuck *("Trying to be perfect often leads to frustration and burnout and makes people stop trying.")*
- Discuss an alternative expectation for consideration *("An alternative to perfectionism is shooting for a goal that is ambitious but realistic.")*

Unhelpful Expectations are Part of DD Stories (See Handout) and Lead to Unhelpful Conclusions

DD Stories and Unhelpful Conclusions

- I'm a bad diabetic (Am powerless to change)
- I can't do this right or perfect. (So why bother trying?)
- I'm an idiot/can't do this/failure. (Am powerless)
- I'm a burden. (Need to keep to self)
- I'm broken/defective. (May be rejected)
- I'm doomed (No point in trying/Am powerless)

Example of A More Helpful Expectation: From Perfectionism to "Healthy Good Enough"

Perfectionistic thinking: has 2 speeds, perfect or failure, not achievable for very long, exhausting, contributes to burnout

Healthy Good Enough

- Personalized
- Ambitious and realistic
- Allows for normal fluctuations, mistakes and experiments
- Sees small steps as valuable
- Focus is on efforts made, not numbers
- Forward looking: What now?

Help Establish Realistic Expectations

"You said that you think that you will never get this right or perfect and this makes you feel like you can't even try. And, this has kept you stuck. Is this right?"

"Yes. If I can't do it right, why even bother trying?"

"Feeling the need to be perfect is a common experience for people with T1D. Unfortunately, perfect is impossible and efforts to achieve perfect outcomes often lead people to feel exhausted, discouraged and diabetes burnout. Does that make sense?"

"I certainly can relate to that. I'm pretty exhausted by it all."

"An alternative to trying to be perfect is to consider a "healthy good enough" goal. This is ambitious, yet realistic. It is personalized to reflect your daily best effort and considers how diabetes fits into your life. It allows for normal BG excursions that go with life with diabetes. How does that sound to you?"

"A healthy good enough – what a concept! I could use that idea in a lot of places in my life. It sounds good."

Poll Question 2

Which of the following does not effectively foster a new perspective?

A. Address unhelpful diabetes beliefs.

B. Distinguish between thoughts/feelings and actions so that other choices can be made.

C. Review plans to increase monitoring of BG.

D. Help make connections between their DD and their management decisions.

Poll Question 3

Which of the following can be helpful in fostering a new perspective?

A. Provide accurate information to counter inaccurate beliefs and perceptions.

B. Consider making a referral.

C. Suggest that they should not be feeling this way.

D. Suggest that they could overcome the problem if they only tried harder.

ReVive5: A Five Step Plan

1. Assess DD regularly and systematically using the T1-Diabetes Distress Scale (T1-DDS).

2. Begin a conversation to foster a new or different perspective.

3. **Consider different management choice(s) that are not driven by tough thoughts and feelings.**

4. Optimize management based on personal choice and values – find the expert within

5. Make changes and plan for next steps

Step 3: Consider A Different Choice Not Driven By DD

Ask how comfortable they are with a new perspective and if they are willing to consider moving forward:

"Given what you have been saying, what do you think that you can do to address this?"

"If you are the boss moving forward, instead of your fear making the choices for you, what would you be willing to try?"

"Your feeling doomed seems to be holding you back from action. If you can consider that are not doomed, what is one thing that you might do differently?"

Step 3: Consider A Different Choice

Remember that THEY are the fixer, not you!

- Have them come up with suggestions for a 'small' change that is important to them.
- Make sure that the change is simple and achievable.
- Only a trial – an experiment for a brief period.
- Recognize and warn them that they will at times slide back – it's OK, it's understandable.
- The tough feelings will continue –but don't have to dictate what they choose to do **– they can feel one way and act another! They are the boss not the DD!**

Step #3: Consider A Different Choice

- Use the person's ideas and let them define what change and how much – even though you may not agree that it will lead to a significant clinical change.
- All change is worth doing!
- It is OK for you to offer ideas and structure to help them implement their change they select (they may need your help).
- Steps 4 and 5 are about trouble shooting BG challenges and helping the PWD identify sensible changes.

Step 3: Consider a Different Choice

"Given what you have been saying, what do you think that you would be willing to do to address this? Are you willing to tolerate some fear to try something new?"

And Sally Responds…

"I would be willing to try the CGM again. I understand they have come a long way since I last used one. And, I could try going to bed with a lower blood sugar."

"That sounds like a very important step! What BG number would you be willing to going to bed with to start and what exactly are you going to do differently? It will help if you have a good plan that you feel confident in."

"I have been making sure I am over 250 mg/dl before bed. I am thinking I could start with going to bed at 200 mg/dl. Maybe I could cut the amount of milkshake I drink in half. Would that be enough?

"Trying out a BG of 200 mg/dl is an important choice. How can you know if half of a milk shake is the right amount for this goal?"

"I can check! This will be easier once I get my new CGM."

"Yes, you may need to experiment a little to get it to the right amount for your goal. When do you plan to start this change?"

"I can start tonight with the half of a milkshake and target for 200 mg/dl before bed. And, I will move forward with the process of getting the CGM today."

"Let me summarize your plan and let me know if I have it all correct. In an effort to face the fear of lows at night and have a BG level that is closer to where you want to be, you are going to start tonight by drinking half a milkshake and go to bed with a BG of 200 mg/dl. You will also move forward with the process of getting a CGM today. Do I have that right?

"Yes. You have that correct. This feels like a weight has been lifted. I've been really stuck and this feels like a plan that I can really do. Thank you."

"I'm really glad. Expect that you will be fearful when you try this out tonight. It is scary to move forward after having a bad low. You have a good plan to begin to regain your confidence. And, thank you for your willingness to share your diabetes story with me. Let's plan to talk by phone next week to discuss how it is going.

Step #3: Consider A Different Choice

Arrange for some kind of follow-up:

- Phone call
- Live or video appointment
- Text

Follow-Up Tasks:

- Trouble shoot problem areas
- Remind them of the key messages
- Build on progress
- Help them decide on next steps (may involve Steps 4 and 5)

Step #3: Consider A Different Choice

- Help them decide on next steps (may involve Steps 4 and 5)
- Steps 4 and 5 are not necessary for everyone.
  At the end of Step 3, some PWD may sensibly choose to:
  - Change to inulin pump or hybrid closed loop system
  - Use CGM
  - See a dietician, personal trainer, or mental health professional

Steps 4 and 5 are most useful when more glucose data are required to identify effective solutions ("My numbers are wacky and are unpredictable!")

ReVive5: A Five Step Plan

1. **Assess DD regularly and systematically using the T1-Diabetes Distress Scale (T1-DDS).**

2. **Begin a conversation to foster a new or different perspective.**

3. **Consider different management choice(s) that are not driven by tough thoughts and feelings.**

4. Optimize management based on personal choice and values – find the expert within

5. Make changes and plan for next steps

You Can Do This!

We know that:

- It seems like a lot to do with a lot of steps and might take too much time.
- You may feel unprepared or uncertain (happens whenever develop a new skill set)
- You don't have to be a mental health professional to do this! Although, you may see things that do need to be referred (MDD, eating disorders, etc.)

Incorporating the emotional side into your program will be more personally rewarding, appreciated by PWDs and lead to better outcomes!

Packet Resources

PDF of slides with conversational tools illustrated
ReVive 5 Worksheet
Common DD Stories
Current Fact-based Info Handout
PDF of T1-DDAS with scoring instructions

Next Session will focus on ReVive Steps 4 and 5

Thank you & Resource Page

Resource Folder for Health Care Professionals

1. Copy of the slides/ handouts
2. 5 Steps Cheat Sheet
3. Diabetes Distress Info
4. Log sheets
5. Articles on carb counting, insulin replacement therapy, exercise and more
6. Resources for people living with type 1 diabetes.

Questions?

- Email us at info@diabetesed.net
- Chat with us @ www.DiabetesEd.net
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